

Quarterly update from research  
and support at MND Scotland



**Friend**, here is an update  
from the support and  
research teams at MND  
Scotland.



A warm welcome to our latest support and research newsletter.

Last month, we launched our [\*\*Manifesto\*\*](#) ahead of the Scottish Parliament election, calling on the next Government to deliver timely, fast-tracked support for everyone in Scotland living with MND. More information and a link to the full document is below and we would encourage you to get behind it and support our asks.

For anyone who requires support with technology, we have partnered with AbilityNet, a UK-wide network of Tech Volunteers who are available to offer free technology support. [\*\*Read more about how AbilityNet can help you.\*\*](#)

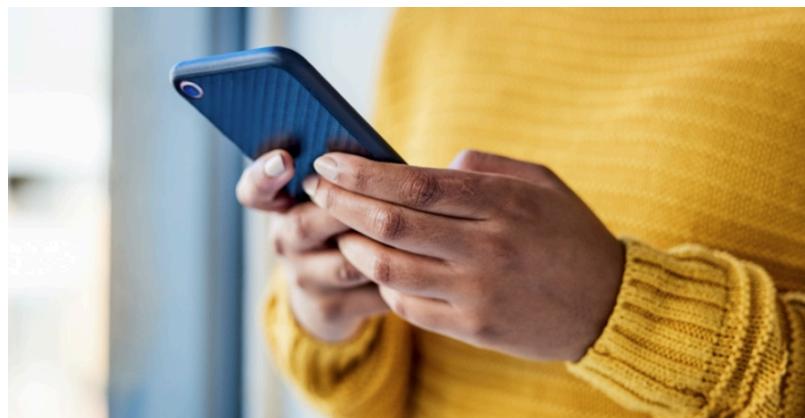
In the next few months, we plan to trial a webinar with one of our funded researchers. Following the success of our LEARN events, we want the MND

community in Scotland to hear directly from researchers and have the chance to ask questions. Once the date is confirmed we will share further details, but please email [research@mndscotland.org.uk](mailto:research@mndscotland.org.uk) if you would like to be kept updated.

Remember, if you need any support, please don't hesitate to contact [support@mndscotland.org.uk](mailto:support@mndscotland.org.uk).

**Nicola Povey, Head of Support Development, and Jane Haley, Director of Research**

## **Results of MND Scotland survey**



Late last year, we asked you to **share your opinions** on the services offered by MND Scotland's support team. We received over 120 responses over the course of 40+ days and have summarised the key findings below:

### **1. We asked which MND Scotland support services people had used or were aware of.**

The most popular service was our welfare & benefits advice, with over three quarters (76%) of respondents having used, or at least being aware of, this service. This was closely followed by our wills and power of attorney support and our

wellbeing grants – both of which were used, or known of, by 69% of respondents. Our counselling service, holiday lodges and aids and equipment grants also scored highly.

**2. We then asked which of our services respondents felt had been the most helpful to them and / or their family.** Here, the grants offer came out on top with almost half (44%) citing this as the most useful support they had received.

Almost a third (29%) felt that getting support with benefits and welfare rights had the most useful impact, closely followed by support with wills & Power of Attorneys (26%). Again, counselling services and the holiday lodges also rated highly – 16% and 13% respectively.

**3. We also asked respondents if they felt there was anything missing from the services we currently offer.** A third (32%) said there wasn't anything they could think of. A desire for additional or broader access to information and support also came across in several replies - with suggestions varying from a support phone line for carers, regular staff updates and photos, to an online forum or chat space.

**4. Lastly, we asked what matters most when people think about support from MND Scotland.** Overwhelmingly, the most popular response here, with more than 1 in 3 (36%) agreeing, was that there is help there when needed - just knowing that someone is there to help, whatever the query. Other matters mentioned more than once included financial support in the form of benefits advice and grants, being swift in response to queries and the ability to demonstrate helpful behaviours, including kindness, understanding and knowledge.

**A few key recurring themes from the survey which could help inform decisions around our future services include:**

- A desire for continued / periodic contact. A few respondents mentioned that whilst initial contact from the support team is fast and thorough, thereafter it can seem slower.
- A need for greater access to general / ad-hoc and emotional support with telephone, online and face-to-face options all cited as being desired.
- A lack of support for children and young people with a person with MND in the family was also highlighted.

Following the survey, we are introducing our new National Support Advisors. This service will offer joined-up welfare and benefits advice, along with support around housing, social care, and navigating statutory services.

Our existing counselling and bereavement counselling services continue, and we are strengthening support for carers by working with local carers' organisations on carers' events, training, and peer support. We will also share local information, including links to virtual counselling and listening services. For those who prefer to access support independently, we will provide clear links and information on our website.

We will also continue offering free wills and power of attorney through Caesar & Howie, and we are adding more online guidance over the coming months. **AbilityNet** is now available to provide tech support across Scotland, and our partnerships with **Home Energy Scotland** and **StepChange** remain in place for energy, money, and debt advice.

Thank you to everyone that responded to our survey. We really appreciate all the feedback you shared.

## Manifesto launch ahead of 2026 election



Ahead of the Scottish Parliament election this Spring, MND Scotland is calling on the next Government to deliver timely, fast-tracked support for everyone in Scotland living with motor neuron disease (MND).

To support our calls, we recently published our [Manifesto](#).

**MND Scotland** is calling on the next government to deliver:

1. Invested in, and fast-tracked, housing and adaptations;
2. Fast- tracked social care;
3. Increased, targeted funding for neuro-progressive conditions.

In the run up to the election, we will be sharing ways you can get involved, such as writing to your MSP and signing our open letter to the next government. You can also support our [Manifesto](#) by spreading the word on social media.

[Read the Manifesto on our website](#)

# Coffee catch-up in Dingwall



MND Scotland is returning to **Dingwall next month** to pilot an informal get together for the local MND community.

For this pilot event, we invite the MND community to come together and share advice, support and a good chat over a cup of tea with peers. The event will also provide a chance to meet and speak to staff from the MND Scotland support team.

## Event details:

- **Hamilton Suite, The Global Energy Stadium**
- **Tuesday, 17 March**
- **1pm - 4pm**

To make sure we have enough tea, coffee and sweet treats, we would appreciate it if you could register your interest using our form: [\*\*MND Scotland get together \(Dingwall\) – Registration of Interest – Fill in form\*\*](#). Please also let us know if you have any dietary or accessibility requirements in the form.

Alternatively, you can get in touch to register interest by emailing [\*\*support@mndscotland.org.uk\*\*](mailto:support@mndscotland.org.uk) or calling us on

0141 332 3903. More information will be available on our website soon.

## **Gordon Aikman scholarship**



**Dr Megan Bolton**, from NHS Greater Glasgow and Clyde, has received a **Gordon Aikman Scholarship**, funded by MND Scotland and the Scottish Government.

The Gordon Aikman Scholarship was set up by MND Scotland and the Scottish Government in 2017, in honour of the late MND campaigner Gordon Aikman, to fund research and developments into improving care and support for people living with MND. Dr Bolton will research the delivery of environmental controls for people with MND across Scotland.

[Read more about Dr Bolton's research](#)

## **Recently published research**



Earlier this month, we shared results of research we funded in 2020 carried out at the University of Edinburgh by **Professor Sharon Abrahams** and **Dr Milena Contreras** into support strategies that could assist people living with MND in making decisions about their health.

The research found that those who have changes in cognition benefit from having specific support strategies when making these decisions.

[Read more about the research here](#)

## FLAIR launches MND pledge

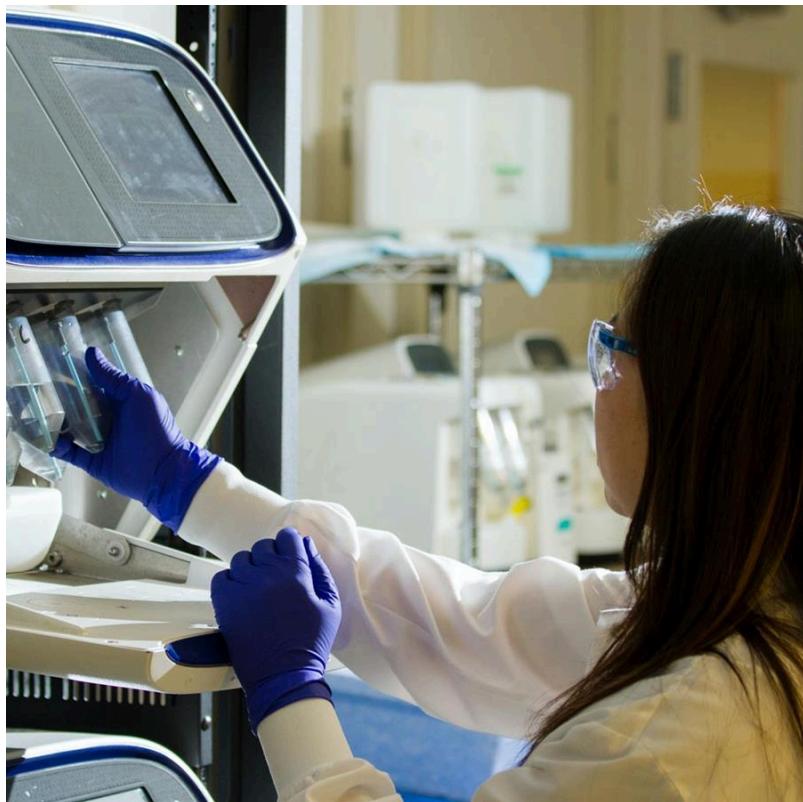


Six housing associations that make up FLAIR, **The Federation of Local Housing Associations in Renfrewshire and East Renfrewshire**, have formally committed to enhancing their service provision for tenants and owners diagnosed with MND in their communities. At the end of last year, FLAIR launched the first-of-its-kind cross-association pledge to support the housing needs of people living with MND.

FLAIR's written pledge sets out a number of commitments, including fast-tracking adaptations and accessible housing allocation processes for those with MND and similar rapidly progressing terminal illnesses within their communities. This means that people with MND will not be added to long waiting lists, as is common practice across the country. Instead, proactive, exceptional approaches will seek to provide the timeliest support possible.

[Read more about the FLAIR pledge](#)

## **Tofersen to treat SOD1-MND**



In December, we shared an update on **tofersen**, a new drug to treat SOD1-MND, a rare genetic subtype of MND, accounting for about 2-3 % of total MND cases in Scotland. [You can read our update here](#).

This year, tofersen will be considered by the National Institute for Health and Care Excellence (NICE) to determine whether it can be provided by the NHS in England. Biogen, the manufacturer of tofersen, also confirmed it is their intention to submit to the Scottish Medicines Consortium (SMC) later in 2026 to be considered for people with SOD1-MND in Scotland.

In the meantime, the tofersen Early Access Programme (EAP) is made available by Biogen to eligible patients in the UK. However, it is extremely disappointing that we don't yet have a tofersen early access programme centre in Scotland. We have been working behind the scenes to support this and will keep everyone updated. In the meantime, if you have received a SOD1-MND diagnosis, please get in touch with [support@mndscotland.org.uk](mailto:support@mndscotland.org.uk).

## And finally ...



As shared in the recent survey results above, you are keen to see more regular staff updates and photos. This is our support team and, over the next few newsletters, we are going to share a bit more about the team - who they are, what they do and how they can support you. Meet Kat, Nicola, Lynsey, Tali and Levon.

We welcome feedback on our quarterly newsletter. If you have any comments or suggestions, please get in touch by emailing [communications@mndscotland.org.uk](mailto:communications@mndscotland.org.uk).



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